Lesson 4

Sources of Routinely Collected Data for Surveillance

Instructor's Guide Form

Lesson Title: Sources of routinely collected data for surveillance

Lesson Goal: For each student to differentiate among various sources of routinely collected data for surveillance

Learning Objectives: By the end of this lesson, the learner will be able to:

1) describe notifiable diseases and related reporting mechanisms

2) describe the following regarding vital statistics - purpose, use, coding, classification, calculation of rates, and quality control examples of surveillance systems based on vital statistics

3) define sentinel surveillance

4) describe the following regarding sentinel surveillance: sentinel health events, sentinel sites, and sentinel providers

5) define registries

6) describe the uses of registries

7) describe the types of registries

8) describe the uses of surveys

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Instructor's Guide Form (continued)

9) differentiate between surveys and registries

10) describe the types of surveys

11) describe the types of administrative data-collection systems

Equipment and Materials Needed:

- Overhead projector
- Transparencies #4.1 - #4.27
- Optional exercise - "Establishing an Injury Surveillance System" (Time required 2-3 hours) - *See end of lesson*

Time required: 90 minutes

Synopsis of Lesson: This lesson reviews sources of routinely collected data that can be used for public health surveillance. It describes notifiable diseases, registries, surveys, and administrative data collection systems.

Adult Education Application: The content of this chapter lends itself very well with a number of adult learning principles, especially the adult learners' desire to relate personal experiences to new material. As you present information on the use of vital statistics, disease registries, provider surveys, etc. you could ask the learners about their previous experiences using these methods. Additionally, you could ask them to describe their assessment of the benefits and liabilities of each method. You could conclude the discussion of the material by setting up a scenario and asking the learners which source of data they would use as their primary surveillance method.

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Sources of Routinely Collected Data for Surveillance

Topical Outline

I. Notifiable diseases and related reporting mechanisms
- A. Brief history of reporting
- B. Determination of diseases for notification
- C. Data collection, transmission, and dissemination
- D. Strengths and limitations

II. Vital statistics
- A. Overview
- B. Birth and death certification
- C. Coding, classification, and calculation of rates
- D. Comparability and quality control
- E. Examples of surveillance systems based on vital statistics and related data

III. Sentinel surveillance
- A. Definition
- B. Sentinel health events
- C. Sentinel sites
- D. Sentinel providers

IV. Registries
- A. Definition and uses
- B. Case series and hospital-based registries
- C. Population-based registries
- D. Exposure registries

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Topical Outline (continued)

V. Surveys

A. Definitions and Uses
B. Differences between surveys and registries
C. Health interview survey
D. Provider-based surveys
E. Other surveys

VI. Administrative data collection systems

A. Means of accessing
B. Factors influencing availability and usefulness of administrative data
C. Integrated health information systems
D. Hospital discharge systems
E. Data collection systems in emergency rooms and other units
F. Ambulatory care and related data

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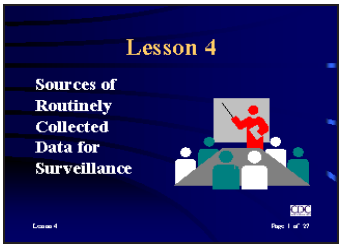

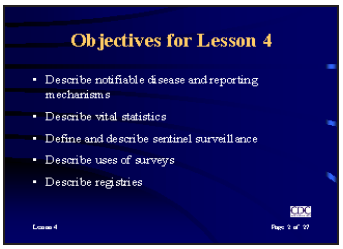

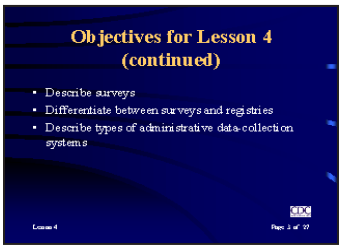

Lesson 4

Sources of Routinely Collected Data for Public Health Surveillance

Content Outline

Lesson Objectives:

- **Describe notifiable diseases and related reporting mechanisms**
- **Describe vital statistics**
- **Define sentinel surveillance**
- **Describe sentinel surveillance**
- **Define registries**
- **Describe uses of registries**
- **Describe types of registries**
- **Describe uses of surveys**
- **Differentiate between surveys and registries**
- **Describe types of surveys**
- **Describe types of administrative data-collection systems**

I. Notifiable disease and related reporting mechanisms

A. Brief history of reporting

1. reporting of notifiable diseases at the U.S. national level
    a. began in 1878 when Congress authorized USPHS to collect morbidity reports
        1) cholera
        2) smallpox
        3) plague
        4) yellow fever
    b. Congress authorized forms in 1902
    c. by 1928, all states were participating in weekly reporting of specified conditions
2. compulsory notification for selected infectious diseases began in other countries in late 1800s

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B. Determination of diseases for reporting

1. National reporting from the states is determined by an agreement between CDC and the Council of State & Territorial Epidemiologists (CSTE)
    a. CSTE is a consortium of epidemiologists from all state and territorial health departments
    b. in 1996, national reporting is required by law for quarantinable diseases
        1) cholera
        2) plague
        3) yellow fever
    c. other diseases to be reported are discussed annually (in 1996, 52 infectious diseases by agreement are reportable to CDC)
    d. each state has its own list of notifiable diseases which is mandated by state law; this list varies from state to state with over 100 infectious diseases being reportable in one state

2. in recent years, notifiable-disease reporting mechanisms have been used to collect information on noninfectious conditions
    a. occupational related conditions are reported in some states
        1) lead poisoning
        2) pesticide poisoning
        3) occupation-related lung diseases
    b. other noninfectious conditions are reportable in some states
        1) spinal cord injuries
        2) Alzheimer's disease
    c. national reporting of vaccine related conditions
        1) since 1988, all health-care providers and vaccine manufacturers have been required to report certain suspected adverse events following specific vaccinations to FDA

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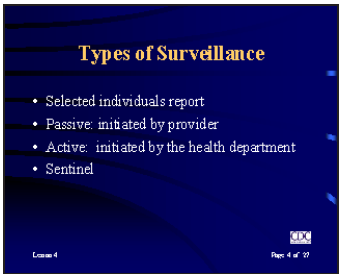
2) Vaccine Adverse Event Reporting System (VAERS) became operational in 1990
3) many countries have adverse drug reaction reporting systems
4) twenty-three countries report to WHO's Collaborating Center for International Drug Monitoring
5) England uses the Prescription Event Monitoring System, funded by public and private sources

C. Data collection, transmission, and dissemination

1. purpose of surveillance system is to direct local, state, and/ or national control and prevention programs

2. information is generally reported by health care providers to local or state health departments
    a. by telephone if immediate response indicated
    b. weekly for other conditions using the telephone or the mail
    c. for some conditions more detailed information especially concerning risk factors is collected and sent to CDC on special forms
    d. can also use absenteeism records for surveillance
        1) schools
        2) industry

3. Surveillance may be:
    a. passive: report initiated by the health care provider (see lessons 3 and 5)
    b. active: report initiated by the health department (see lessons 3 and 5)
    c. sentinel: selected individuals report



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4. National Notifiable Diseases Surveillance System (NNDSS)
    a. the reporting of the 52 notifiable infectious diseases (1996) from state health departments to CDC
    b. personal identifiers are not included

5. National Electronic Telecommunications System for Surveillance (NETSS)
    a. means for electronic transmission to CDC
    b. began in 1985
    c. since 1990, all states report by NETSS

6. Morbidity and Mortality Weekly Report (MMWR)
    a. published by CDC
    b. reports national case counts for most notifiable diseases the week after reported to CDC
    c. available by printed or electronic report

7. most state health departments disseminate surveillance data and public health information through weekly or monthly reports

8. surveillance for zoonotic diseases
    a. also involves monitoring animal hosts that either transmit disease directly to humans or are susceptible to the disease
        1) includes encephalitis
        2) rabies
        3) Rocky Mountain spotted fever
        4) Lyme disease
9. role of laboratories in reporting notifiable conditions
    a. becoming increasingly important
    b. many states have developed reporting requirements for laboratories
    c. comprehensive nationwide reporting by laboratories is being developed in response to emerging infections

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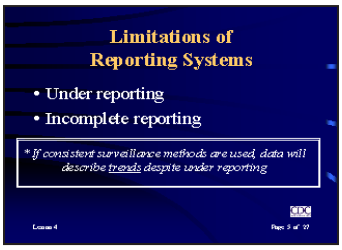
d. in England, Wales, and Northern Ireland microbiological laboratories voluntarily report positive identifications of selected conditions to the national Public Health Laboratory Service (PHLS)

D. Strengths and limitations



1. under-reporting
    a. consistent and well-characterized problem of notifiable-disease reporting systems
    b. in U.S., estimates of completeness of reporting range from 6% to 90% for many common notifiable diseases
    c. reporting generally more complete for conditions with serious consequences (rabies, plague) or rare diseases (diphtheria, tetanus)
    d. if the methods used in the specific disease surveillance system are consistently used the data will describe trends, even if there is under reporting

2. factors contributing to incomplete reporting

    a. lack of medical consultation for mild illnesses
    b. concealment by patients or health-care providers of conditions that might cause social stigma
    c. lack of awareness of reporting requirements
    d. lack of interest by the medical community
    e. incomplete etiologic definition of notifiable conditions
    f. inadequate knowledge of case definitions for surveillance purposes
    g. variation in clinical expertise in diagnosing conditions in different areas
    h. changes in procedures for verifying reports from providers

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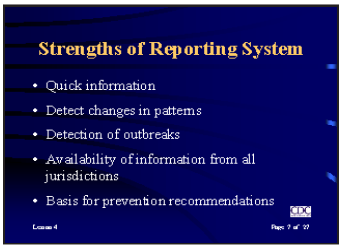
i. variation in use of laboratory confirmation-for example: drug resistant Salmonella newport
j. variation in laboratory procedures
k. low priority for reporting by health officials at local and state levels

3. ways to improve reporting
    a. increase usefulness of data for local decision making
    b. case investigations
    c. outbreak investigation
    d. media coverage of an event
    e. development of standardized case definitions
    f. training

4. extent of under-reporting varies by risk group
    a. in Philadelphia under reporting ofAIDS was more prevalent for those employed in white-collar occupations with private health insurance
    b. STDs are under reported by private physicians; better reported by clinics.
5. in spite of limitations, surveillance systems based on reporting of notifiable conditions are a mainstay of public health surveillance
    a. information is available quickly
    b. information is available from all jurisdictions
    c. knowledge of specific characteristics of reporting for a particular condition is necessary for interpreting findings
    d. notifiable-disease systems can detect outbreaks or other rapid changes in a timely manner so that control activities can be initiated
    e. initial observations can be evaluated by surveillance



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f. notifiable-disease systems can detect changes in patterns of disease by demographic characteristics or risk groups. For example, HIV/AIDS surveillance systems have identified new risk groups (IV drug abusers, children)

g. evaluation of surveillance information led to changes in strategies for disease control and prevention
    1) changes in recommendations for measles vaccination
    2) changes in recommendations for hepatitis B vaccination

h. data are important for developing health education strategies.

i. reports of adverse drug reactions are important in
    1) defining problems
        a) increase of paralytic poliomyelitis among recently vaccinated children in 1955
        b) increase in Guillain-Barre' syndrome following vaccination for swine influenza in 1976
    2) resulting in
        a. labeling changes
        b. drug withdrawals

j. notifiable-disease reporting mechanisms important for obtaining preliminary assessment of public health impact of prevalent conditions
    1) HIV/AIDS
    2) toxic-shock syndrome
    3) Legionnaire's disease
    4) Reye syndrome
    5) eosinophilia-myalgia syndrome (EMS)

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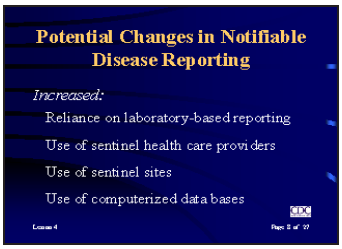

6. potential changes in notifiable-disease reporting
    a. increased reliance on laboratory-based reporting
    b. increased use of sentinel health-care providers
    c. increased use of sentinel sites
    d. use of computerized data bases developed for billing and other purposes; however, utility of these is limited at present
        1) International Classification of Disease (ICD) codes are often not used to identify infectious agents on billing records
        2) information in large data bases not available immediately

II. Vital Statistics

A. Overview

1. systematic registration of vital events such as the plague had its origins in parish registers of fifteenth century Western Europe
    a. Bills of Mortality begun in 1532 was a weekly tally of persons who died in London from plague and other causes
    b. John Graunt was one of the first to use numerical methods to study patterns of mortality

    b. 1989 model birth certificate includes information on perinatal risk factors to help improve surveillance for perinatal events

2. in 19th century, parish registers in Great Britain were superseded by civil registers kept for legal purposes

3. use of standard procedures for collecting, coding, and reporting vital events was first used systematically by William Farr in Great Britain in 1830s

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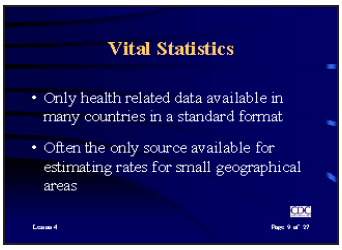
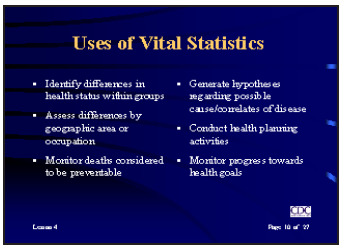
a. Farr developed nomenclature and statistical classification systems
b. Farr's work with Marc d'Espine form the basis of the international disease classification system used today

4. important to surveillance
    a. information collected at time of birth
    b. information collected at time of death

5. about 80 countries or areas report statistics on vital events to WHO
    a. coded and tabulated according to ICD-9
    b. represents about 35% of the deaths that occur each year worldwide



6. vital statistics often are:
    a. the only health-related data available in many countries in a standard format
    b. the only source of health information available for the entire population
    c. the only source available for estimating rates for small geographic areas



7. uses of vital statistics
    a. to monitor long-term trends
    b. to identify differences in health status within racial or other subgroups of the population
    c. to assess differences by geographic area or by occupation
    d. to monitor deaths that are generally considered preventable
    e. to generate hypotheses regarding possible causes or correlates of disease
    f. to conduct health planning activities
    g. to monitor progress toward achieving improved health of the population

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8. usefulness of vital statistics
    a. depends on the characteristics of health event
    b. depends on procedures used to collect, code, and summarize relevant information
    c. generally, vital statistics will be more useful for conditions that can be ascertained easily at the time of birth or death
    d. mortality rates derived from death certificate data will more closely approximate the incidence for conditions
        1) with a short clinical course that are easy to diagnose
        2) are easily identified as initiating a chain of events leading to death
        3) are usually fatal
    e. process of producing final vital statistics at a national level can take several years

B. Birth and death certification

1. responsibility for registration of birth, death, and fetal death is vested in individual states and in certain independent registration areas

2. states are encouraged to adopt standard certificates similar to the model certificate developed by NCHS in collaboration with other groups; some states modify to meet own needs

3. certificates are usually filed with a registrar within 24 hours in the jurisdiction in which the event occurred

4. birth certificates
    a. for birth certificates, the physician or attendant certifies date, time, place of birth, and other hospital personnel usually obtain information on the reminding items

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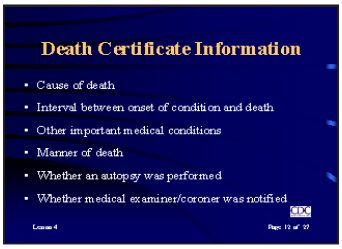

5. death certificates
    a. funeral director is usually responsible for including all personal information about the decedent and for assuring that medical information is provided by the physician who certifies the death
    b. information provided by physician
        1) cause of death
        2) interval between onset of condition and death
        3) other important medical conditions
        4) manner of death
        5) whether an autopsy was performed
        6) whether the medical examiner or coroner was notified of the death
    c. local registrars
        1) assure that all vital events that occurred in the jurisdiction are registered
        2) assure that the required information is provided on certificates before they are sent to state registrar
    d. state registrars
        1) number, index, and bind certificates for permanent safekeeping
        2) forward certificates for deaths of nonresidents to their states of residence

C. Coding, classification, and calculation of rates

1. calculation of national death rates
    a. for infant and maternal mortality rates, number of live births is used as the denominator
    b. for other death rates, estimate of total population is used as the denominator
    c. related specific rates can be developed such as gender, race, etc.

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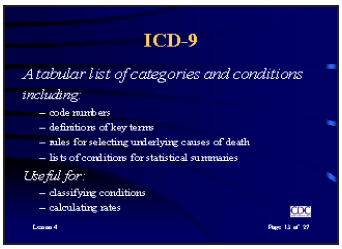

2. ICD-9
    a. tabular list of categories and conditions and includes
        1) code numbers
        2) definitions of key terms
        3) rules for selecting underlying cause of death
        4) lists of conditions for statistical summaries
    b. used to classify conditions
    c. used to calculate rates

3. age-standardized rates
    a. calculated when summary rates are compared
    b. controls for the effects of differences in age structure between compared populations
    c. age distribution of U.S. population in 1940 used as standard

4. for international comparisons, other age distributions often used such as
    a. world standard population
    b. European standard population

5. final national mortality and natality data
    a. available from NCHS several months after the close of a calendar year
    b. 10% sample of deaths is available within a few months
    c. final data are often available more quickly from individual states
    d. about half of states in U.S. submit both medical and demographic data from certificates to NCHS in computerized form
    e. for countries reporting to WHO, final mortality and natality data with indices of quality and completeness are available within 2 - 3 years

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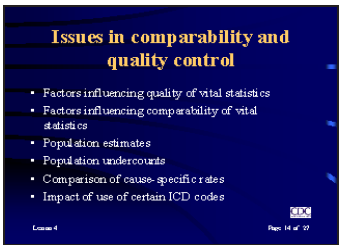

D. Comparability and quality control

1. factors influencing the quality of vital statistics information
    a. completeness of registration
    b. relevance of categories used for diseases, injuries, other conditions
    c. accuracy of demographic and medical data provided on certificates
    d. translation of information into computerized data
    e. appropriate coding and categorization
    f. accuracy of population estimates or other estimates used for denominator

2. factors influencing comparability of vital statistics
    a. differences in access to medical care
    b. diagnostic practices
    c. interpretation of coding rules

3. population estimates
    a. available for about 220 countries or areas of the world through the United Nations
    b. usually derived from censuses conducted at regular intervals (usually every 10 years) in which total population is enumerated intercensal estimates are derived by adjusting census figures for birth, death, and migration patterns in intervening years
    c. in some countries, population estimates are derived from surveys or from continuous population registers

4. population undercounts
    a. can have a measurable impact on death rates
    b. rates will be inflated if population estimate used for denominator is too small

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1) example: in U.S., the 1980 age-adjusted death rate from all causes would decrease by 1.1% if the population estimate from the 1980 census were adjusted for under-counts
2) effects are greater for subgroups of the population: for homicides and deaths resulting from legal intervention in the U.S. in 1980, adjustment for census under-count would change the ratio of death rates for black to white men ages 35-39 years from 7.3 to 6.2 - a decrease of nearly 18%

5. comparison of cause-specific rates
    a. extent to which information on birth and death certificates is reported completely and accurately will have an effect
    b. precision of population estimates will have an effect
    c. impact will be of less importance for aggregated cause-of-death categories
    d. comparisons between different geographic areas or different population subgroups should be interpreted cautiously

6. impact of use of certain ICD codes
    a. mortality from "signs, symptoms, and ill-defined conditions" (*ICD-9* 780-790) is often used as an indicator of care and consideration given by medical certifiers to completing certificates
        1) wide range of use of this code
            a) less than 1% inAustralia, Finland, Hungary, New Zealand, Sweden, United Kingdom

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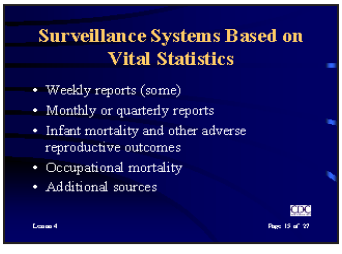
b) 5% - 10% for Belgium, France Greece, Israel, Poland, Portugal, Yugoslavia
c) 1.4% in 1988 in U.S. with a range among states of 0.4 % - 4.1%

b. approaches to facilitate improvement in quality of information on birth and death certificates
   1) providing physicians and funeral directors clearer instructions for completing certificates
   2) more effective training regarding the importance of vital statistics and importance of following recommended procedures for completing both the medical and demographic section of certificates
   3) state and local registrars can increase the extent to which they contact physicians and funeral directors when additional information is needed
   4) state and local registrars can facilitate amendment of certificates when additional information is available from autopsies or other sources
   5) in spite of limitations, birth and death certificates are an important source of information for surveillance of some health events

E. Examples of surveillance systems based on vital statistics and related data



1. Weekly reports
   a. 121-City Surveillance System (U.S.) for deaths
      1) operational since 1952
      2) part of national influenza surveillance effort

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3) 121 cities report to CDC each week the total number of deaths and the number attributed to pneumonia and influenza by age group
4) published within a week in *MMWR*
5) system detects short-term increases in deaths from influenza and pneumonia in a timely manner as needed for public health intervention
6) increases from other causes such as increased deaths from heat wave related mortality have been detected

2. monthly or quarterly reports
    a. final mortality data not available for approximately 2 months
    b. Monthly Vital Statistics Report (MVSR)
        1) published by NCHS, provides provisional estimates within 3-4 months of final mortality data
        2) state registrars submit Current Mortality Sample to NCHS each month
            a) Current Mortality Sample is a 10% systematic sample of death certificates
    c. Mortality Surveillance System (MSS)
        1) time-series regression models fitted using monthly data
        2) charts displaying monthly estimates and the fitted model for specific conditions are published each month in the *MVSR*
    d. benefits of Current Mortality Sample and MSS
        1) monitor overall trends in total mortality

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2) monitor trends in relatively common causes of death that are increasing or decreasing over time
    a) heart disease
    b) homicide
    c) lung cancer
    d) HIV/AIDS
    e) changes in mortality for conditions where supplemental information is often needed should be interpreted with caution

3. infant mortality and other adverse reproductive outcomes
    a. collected to assess potentially preventable mortality by geographic area and within sub-groups of the population
    b. information is useful for health planning and for targeting services, since U.S. infant death rates vary considerably by geographic area and within demographic subgroups
    c. information on birth certificates has been used to identify high-risk mothers who need supportive services for infant care
        1) in Michigan, information on birth certificates is transmitted electronically from hospitals to the state health department
        2) key information is then sent to county health departments so that public health nurses can be assigned to geographic areas with the greatest need

4. occupational mortality
    a. Farr was first to evaluate systematically the associations between occupation and cause of death

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b. *The Decennial Supplement on Occupational Mortality for England and Wales* has been published approximately every 10 years since 1855
c. occupation-specific mortality rates are useful for identifying occupations for which detailed studies may be warranted
d. in the U.S., occupation and industry are usually included on standard death certificate
    1) states are not required to report
    2) if reported, information included in national final mortality files
e. National Traumatic Occupational Fatalities (NTOF) surveillance system
    1) provides data to CDC's National Institute for Occupational Safety and Health (NIOSH)
    2) these data include additional information for work-related traumatic deaths that is included on death certificates but that is not coded and computerized routinely in all states
f. state and industry-specific rates are derived using estimates of the employed population from the Bureau of Labor Statistics
g. analyses from NTOF suggest that traumatic occupational fatality rates decreased in U.S. between 1980-1985. In some instances, large differences were found in fatality rates by gender and by state within the same industry

5. supplement information from other sources
    a. in the U.S., medical examiners and coroners are responsible for investigating sudden and unexpected deaths (approx. 20% of all deaths per year)

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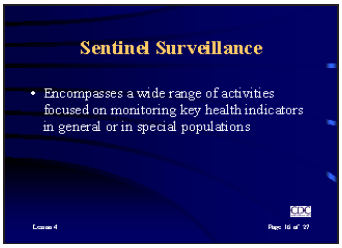
1) The Medical Examiner/Coroner Information Sharing Program reports include detailed information on circumstances surrounding death, results of laboratory analyses for alcohol and drugs, and other relevant information
2) these reports are used to investigate deaths associated with horseback riding, drug abuse, hurricanes, earthquakes, and heat waves

b. Fatal Accident Reporting system (FARS) has been used to investigate association between use of child restraints and motor vehicle related crashes and the association between premature mortality and alcohol-related traffic crashes
c. uniform crime-reporting registries in U.S. and Canada
    1) used to investigate relationship between homicide and prevalence of handgun ownership
    2) maintained by FBI in U.S. and Centre for Justice Statistics in Canada
    3) other sources (police, ambulance, fire reports) may be included

III. Sentinel surveillance

A. Definition



1. encompasses a wide range of activities focused on monitoring key health indicators in general or special populations

2. primary intent is to obtain timely information not available from other sources needed for public health or medical action in a relatively inexpensive manner

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3. sentinel refers to:
    a. key health events that may serve as an early warning or represent the tip of the iceberg
    b. clinics or other sites where health events are monitored
    c. reporters who note the occurrence of a disease or diseases
        1) in clinics or other sites where health events are monitored
        2) in networks of health-care providers who agree to report information on one or more health events

4. Rutstein's definition of sentinel health event: "preventable disease, disability, or untimely death whose occurrence serves as a warning signal that the quality of preventative and / or therapeutic medical care may need to be improved"

5. Woodhall states that sentinel surveillance represents: "an attempt to find a system that would provide a measure of disease incidence in a country in the absence of good, nationwide, institution-based, surveillance without having to resort to a large expensive survey"
6. in Europe, routine morbidity surveillance is often conducted by networks of primary-care providers who routinely report information on conditions that are relatively common in general practice

B. Sentinel Health Events

1. sentinel health event surveillance for maternal mortality (U.S.)
    a. first used in NYC in 1930s
    b. associated with a rapid decline in mortality associated with childbirth

2. monitoring preventable conditions can highlight more general problems

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a. review of deaths among infants from hemolytic disease
b. indicated that mothers of many affected infants did not have medical insurance coverage and thus did not receive adequate prenatal care

3. quality of care has been evaluated using conditions for which death or disability could have been prevented

4. sentinel health event surveillance activities have been useful for identifying health events that may be related to occupational exposures
    a. lists of occupation-related health events have been developed
    b. some of which are specifically tied to environmental or occupational exposure such as angiocarcinoma of the liver and mesothelioma

5. Sentinel Event Notification System for Occupational Risks (SENSOR)
    a. program developed by the National Institute of Occupational Safety and Health (NIOSH)
    b. focuses on surveillance of specific occupational conditions by networks of sentinel providers such as silicosis, occupational asthma, etc.
    c. primarily used for case identification and follow-up
    d. information from SENSOR projects may augment other sources of information on trends for occupation-related disorders
6. infant mortality used to monitor availability and quality of medical care in all countries

7. U.S. established goals and objectives using key health indicators
    a. to compare progress toward reducing preventable morbidity and mortality

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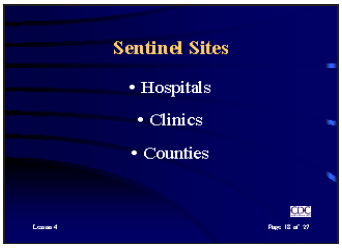
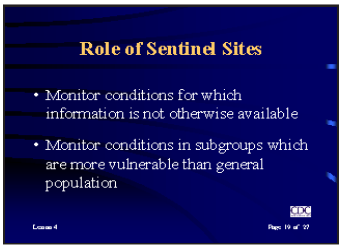
b. to monitor achieving year 2000 objectives

8. WHO's Health forAll activity
    a. 22 key health indicators that are monitored routinely since 1986
    b. used to assess general health of population in Europe

C. Sentinel sites



1. sentinel hospitals, clinics, counties
    a. can provide timely information on a wide range of health conditions that is not available from other sources
    b. WHO Expanded Project on Immunization uses sentinel hospitals and clinics in 25 target cities to monitor the impact of vaccination on the incidence of neonatal tetanus, poliomyelitis, diphtheria, measles, pertussis, and tuberculosis
    c. after initial contact with sites, officials choose sentinel sites that serve populations as similar as possible to the general population



2. role of sentinel sites
    a. monitor conditions for which information is not otherwise available
    b. monitor conditions in subgroups that may be more vulnerable that the general population
    c. example: hepatitis data from four county health departments are used to develop data concerning hepatitis B & C
    d. example: HIV data from special clinics that see high risk patients
    e. obtain more specific and accurate data than usually available through the MMWR surveillance system

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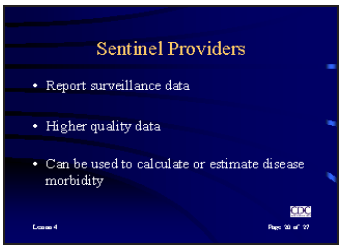

D. Sentinel providers

1. role
    a. report surveillance data on selected diseases that are used by state or national health agencies
    b. provide higher quality and timely information for surveillance
    c. primary-care practitioners report timely information because they generally provide the first professional judgment for medical problems that are seen in early stages
    d. in most networks, primary-care physicians report a minimum amount of information usually at weekly intervals on a select group of health events that are relatively common in general practice including
        1) some infectious diseases
        2) dementia
        3) gastric ulcers
        4) multiple sclerosis
        5) acute pesticide poisoning
        6) drug abuse
        7) requests for mammography, cervical smears, HIV tests
    e. extent to which rates that reflect morbidity in general population can be calculated is related, in large part, to the manner in which medicine is organized and practiced in that reporting area, and to the manner in which the sentinel reporters are selected
    f. most enduring networks are characterized by highly motivated volunteer providers who report information consistently over time

2. Eurosentinel
    a. consortium funded by European Economic Community

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b. coordinates activities of sentinel general practitioner networks
c. 1990 survey indicates that there were at least 39 active networks in Europe
d. serves as clearinghouse for a wide range of activities that highlight similarities and differences between countries
e. goal is to establish a computerized European sentinel-practice network

3. Great Britain
    a. Weekly Returns Service
        1) organized by Royal College of General Practitioners
        2) continuous operation since 1962
        3) report conditions for about 1% of population
        4) in 1990, 242 volunteer general practitioners reported weekly incidence data for 44 conditions
        5) rates per thousand can be calculated using information from patient lists
        6) particularly useful for monitoring trends in influenza and related illnesses in Great Britain
    b. Surrey University Morbidity Network
        1) also covers about 1% of population in Great Britain
        2) operational since 1974
        3) examines seasonal and other environmental influences on morbidity

4. Netherlands
    a. Netherlands Institute of Primary Health Care (NIPHC) is a network of sentinel general practitioners
    b. covers about 1% of population
    c. gathers reliable epidemiologic data on health problems

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d. gathers information on actions taken by providers to address problems

5. Belgium
    a. Belgian Sentinel Practice Network, operated by National Health Department since 1979
    b. covers an estimate 1.3% of population
    c. dissemination is a strength of program
        1) bimonthly and annual reports to participating practitioners, to Ministry of Public Health, to medical and public health schools, to professional organizations, and to the press

6. France
    a. French Communicable Diseases Computer Network (FCDCN) uses interactive electronic systems
    b. networks of sentinel primary-care providers transmit and receive information on selected conditions using computers
        1) operated by National Health Department and National Institute of Health since 1984
        2) about 1% of population covered
        3) trends are expressed as average number of cases per reporting physician per week
        4) information is also transmitted directly by national, hospital, and other laboratories
        5) very effective in tracking spread of influenza-like illness

7. United States
    a. network of 139 sentinel physicians report cases of influenza-like illness each week during influenza season to CDC. Nasopharyngeal specimens sent to a central laboratory which reports to physicians and CDC.

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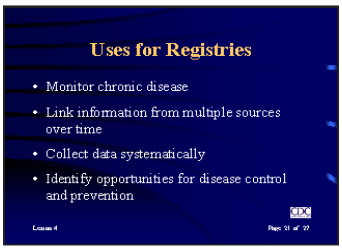
b. the National Nosocomial Infection Surveillance Program (NNIS) collects surveillance data on nosocomial infections from 250 acute care hospitals.

8. Ambulatory Sentinel Practice Network (ASPN)
    a. clinicians from U.S. and Canada - mainly family practitioners, many of whom practice in rural areas
    b. conduct collaborative research projects
    c. conduct surveillance

9. Pediatric Research in Office Settings (PROS) network
    a. formed in 1985
    b. sponsored by American Academy of Pediatrics
    c. 740 practitioners in 224 practices
10. international collaborative organizations
    a. International Primary Care Network (ICPN)
    b. European Electronic Adverse Drug Reaction Network (EEADRN)
    c. Eurosentinel

IV. Registries

A. Definition and uses



1. popular for monitoring the public health impact of chronic diseases

2. information from multiple sources is linked for each individual over time

3. information is collected systematically from diverse sources
    a. hospital discharge abstracts
    b. treatment records
    c. pathology reports
    d. death certificates

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4. information is consolidated for each individual so that each new case is identified and cases are not counted more than once

5. case series can be used for descriptive analyses and assessment of treatment effectiveness

6. population-based registries can be used to determine incidence rates and have been useful for surveillance activities

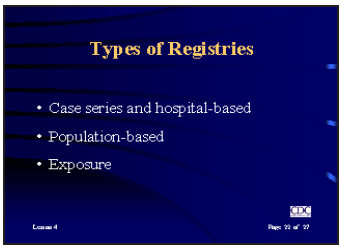
7. most successful registries have explicit and realistic purposes and accurately collected data that are limited to essential information

8. complexity of registry limits extent to which data can be made available rapidly

9. used to monitor a wide range of health events such as exposure to hazardous agents and commonly for surveillance of cancer

10. have identified opportunities for disease control and prevention activities

B. Types of registries



1. case series and hospital-based registries
    a. commonly used to provide information that can be used to improve patient care such as for cancer patients
    b. can be used to study relatively rare conditions
        1) mesothelioma among those exposed to asbestos
        2) adenocarcinoma of the vagina among women exposed prenatally to diethylstilbestrol
    c. hospital-based trauma registries are recent developments

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2. population-based registries
    a. by using incidence rates, population-based registries can estimate occurrence of health event over time in different geographic areas and population subgroups
    b. descriptive analysis of incidence rates based on registry information
        1) can be used for health planning purposes
        2) can suggest etiologic hypotheses for further evaluation
        3) can be used to estimate effectiveness of some control or prevention measures
    c. findings from studies can encourage physicians to abandon less than effective individual therapies, thus improving the standard of medical care

3. exposure registries
    a. used to assess effect on a specific population of exposure to physical, chemical, and biologic agents for example, registries of survivors of atomic bombing of Hiroshima and Nagasaki during WWII and their offspring.
    b. used to assess risk of illness for general population groups exposed to specific agents for example: registry of general population exposed to polybrominated biphenyls through contamination of dairy cattle food supplements in Michigan
    c. The Agency for Toxic Substances and Disease Registry is mandated by U.S. Congress to address public health problems associated with environmental exposures to hazardous waste sites and chemical spills, partly through the creation of registries.

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4. outcome registries
    a. cancer registries
        1) Connecticut Tumor Registry, oldest population-based cancer registry in U.S.; developed to support goals of service-oriented hospital-based cancer registries throughout the state
        2) Surveillance, Epidemiology, and End Results (SEER). National Cancer Institute (NCI) collects information from specific population based cancer registries (since 1973) is largest population-based registry in the Western world
        3) goals of SEER to estimate cancer-related incidence and mortality in U.S.; to identify unusual changes in incidence of specific types of cancer over time in designated areas or demographic subgroups; to describe changes in extent of disease at diagnosis and to estimate patient survival; and to foster studies of cancer risk factors, screening, and prognostic factors to allow intervention
    b. descriptive analyses regularly performed and published
        1) there are a total of 42 cancer registries throughout the U.S.
        2) European registries include: Denmark, Belgium, England and Wales, and Scotland
    c. International Agency for Research on Cancer (IARC)

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1) part of WHO
2) collects information from cancer-incidence registries around the world
3) by 1989, there were 238 population based registries in 53 countries

d. strengths and limitations
1) limited usefulness for identifying new hazards
2) helpful in identifying cases that were evaluated in more extensive epidemiologic investigations
3) provide important information for a wide range of public health activities

3. birth-defects registries
a. the U.S. system, the Birth Defects Monitoring Program (BDMP) uses vital statistics and hospital discharge data to monitor trends (CDC's example of passive monitoring)
b. CDC operates Metropolitan Atlanta Congenital Defects Program (MACDP)
1) all births are monitored in 5 county metropolitan area
2) is an active case finding system
3) publishes regular reports
4) investigations are conducted using these data, such as peri-conceptual vitamins use in preventing neural tube defects

c. Europe
1) European Registry of Congenital Abnormalities and Twins (EUROCAT), funded through Economic Community
2) International Clearinghouse for Birth Defects Monitoring Systems

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(ICBDMS)

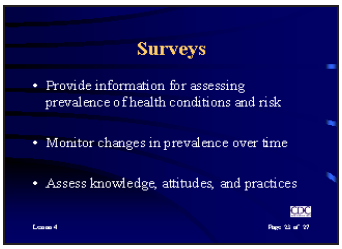
a) funded by WHO
b) disseminates birth-defects data from surveillance systems around the world
c) provides a forum for rapid dissemination of information on teratogens

d. recent developments

1) registries are being developed in some local communities to monitor local preschool children needing early intervention
2) examples include fetal alcohol syndrome, cerebral palsy, and mental retardation
3) useful for monitoring effectiveness of services

V. Surveys

A. Definitions and Uses



1. surveys are not surveillance but can support surveillance activities.

2. surveys collect specific data from a selected population either at one time or at intervals. If repeated often enough and at regular intervals, they can be used for surveillance purposes.

3. surveys provide useful information for assessing prevalence of health conditions and potential risks

4. surveys monitor changes in prevalence over time

5. surveys assess knowledge, attitudes and health practices in relation to certain conditions

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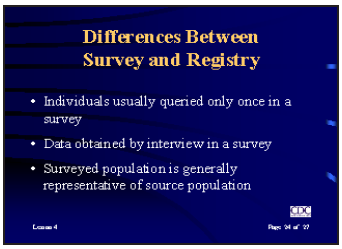

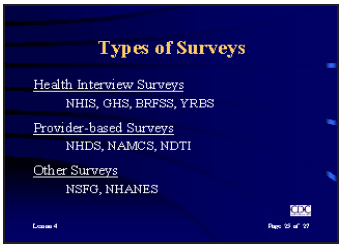

B. Differences between surveys and registries

1. individuals usually queried only once in a survey

2. data obtained by interview in a survey

3. attempt to assure that surveyed population is representative of the source population

4. registries - numerator data; surveys - denominator data

C. Health interview surveys

1. National Health Information Survey (NHIS)
    a. conducted annually since 1957
    b. provides information on self-reported illnesses, chronic conditions, injuries, impairments, use of health services, and other health-related topics for civilian, non-institutionalized population
    c. households are identified through a complex sample design involving clustering and stratification
    d. respondents are interviewed in the home
    e. annually, information collected on about 122,000 people from 48,500 households
    f. interview has a core set of health and socio-demographic questions and a supplemental section for detailed information on specific health topics

2. Behavioral Risk Factor Surveillance System (BRFSS)
    a. collaboration between CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCHPHP) and state health departments
    b. telephone surveys regarding adult health behavior and use of prevention services

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c. purpose is to support state prevention initiatives

3. Youth Risk Behavior Survey (YRBS)
    a. developed and implemented by NCCDPHP
    b. focuses on efforts of local, state, and federal agencies that monitor behavior of young people
    c. monitors changes in types of behaviors

4. General Household Survey (GHS)
    a. conducted in England, Scotland, Wales
    b. obtains information on housing, employment, education, health, use of social services

D. Provider-based surveys

1. National Center for Health Statistics (NCHS) surveys
    a. National Hospital Discharge Survey (NHDS): collects data from a sample of non-government, short stay hospitals
    b. National Ambulatory Medical Care Survey (NAMCS): collects data from a sample of non-government office-based physicians
    c. monitor characteristics of health encounters

2. National Disease and Therapeutic Index (NDTI)
    a. example of a proprietary data base
    b. provides ongoing data on conditions seen in ambulatory-care settings
    c. used primarily by pharmaceutical industry

E. Other surveys

1. National Survey of Family Growth (NSFG)
    a. provides national data on demographic and social factors associated with childbearing, adoption, and maternal and child health

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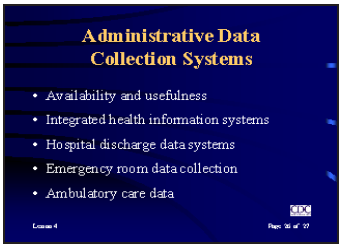
b. based on household interviews of women of childbearing age

2. National Health and Nutrition Examination Survey (NHANES)
    a. provides extensive information on prevalence of chronic conditions, distribution of physiologic and anthropomorphic measures and nutrition status
    b. used primarily for epidemiologic and related analyses
    c. used to provide point estimates to monitor changes over time in health outcomes
3. serological surveys can provide disease prevalence data such as HIV and HBV surveys



VI. Administrative data-collection systems

A. Means of accessing

1. computerized data base for billing purposes

2. hospitalizations

3. visits to emergency rooms

4. visits to community health-care providers

B. Factors influencing availability and usefulness of administrative data

1. type of information that is computerized

2. extent to which uniform classification schemes are used for categorizing

3. availability of sufficient computer capacity and user-friendly software programs to process large amounts of data

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4. extent to which supplementary information can be obtained

5. extent to which information for individuals from different administrative sources or time periods can be linked

6. length of time between the occurrence of the health event and availability of data

C. Integrated health-information systems

1. available in Sweden, Canada, and for limited groups in U.S.

2. data on individuals are consolidated from a variety of sources

D. Hospital-discharge data systems

1. routinely collected and computerized using standard data-set formats
    a. Recommended Minimum Basic Data Set (RMBDS) for European community
    b. Uniform Hospital Discharge Data Set (UHDDS) or Medicare Uniform Bill-82 (UB-82) in U.S.

2. U.S. acute care hospitals required by the Joint Commission on Accreditation of Healthcare Organizations to report information on diagnoses, length of stay, and inpatient services

3. Private-sector systems
    a. Commission on Professional and Hospital Activities (CPHA)

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1) abstracts information from clinical records of U.S. hospitals
2) Professional Activities Study (PAS) has a data base that includes more than 200 million records

b. Birth Defects Monitoring Program (BDMP)
1) provides information from newborn discharge summaries for about 25% of births in U.S.
2) prevalence rates are calculated using number of live births as the denominator

c. other systems are ongoing throughout the U.S. to obtain data concerning specific health problems

4. federal data-collection systems

a. Medicare Provider Analysis and Review (MEDPAR)
1) created by HCFA, based on claims submitted for medicare patients
2) monitors the quality of care provided through Medicare program
3) cleaned data reorganized to have one record per hospitalization
4) because based on claims, no data are available for patients enrolled in capitated managed care (HMOs) systems.

b. National Claims History File (NCH) (being created for elderly medicare recipients linked to individuals)

c. both contain only ICD-9 codes and no other clinical data; they are useful for looking at health outcomes but not at processes of care (i.e. not particularly useful for looking at quality of care)

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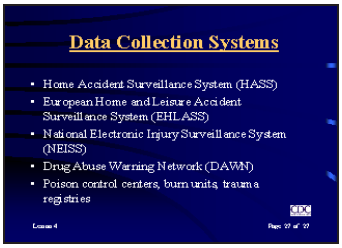

E. Data collection systems in emergency rooms and other units

1. General
    a. used for surveillance of a variety of acute health events
        1) nonfatal injuries
        2) illicit drug use
        3) poisonings
        4) adverse reactions to prescription drugs
    b. not routinely computerized and reported in a standard format
    c. limited scope

2. Examples
    a. Home Accident Surveillance System (HASS)
        1) England and Wales
        2) Information collected by trained clerks
    b. European Home and Leisure Accident Surveillance System (EHLASS)
        1) similar to HASS
        2) implemented in all European Economic Community countries
    c. National Electronic Injury Surveillance System (NEISS)
        1) collects information on consumer product-related injuries, poisonings, burns from emergency room records of sample of hospitals
        2) information sent daily to CPSC
    d. Drug Abuse Warning Network (DAWN)
        1) NIDA
        2) uses reports from hospital emergency rooms and medical examiners or coroners' offices
        3) used to detect emerging trends in nature and severity of drug abuse problems

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e. Poison-control centers, burn units, trauma registries
    1) not available routinely in standard format
    2) efforts are underway to create minimum data sets and reporting formats

F. Ambulatory care and related data

1. not generally available from administrative sources from all segments of the population (except in Sweden and Canada)

2. data concerning non-hospitalized conditions are obtained by periodic surveys and sentinel surveillance systems

3. Uniform Ambulatory Care Data Set (UACDS)
    a. U.S. program not widely used
    b. offers possibility for standardization of ambulatory care data
    c. difficult to maintain an up-to-date outpatient procedure classification system

4. Medicare data and other state managed health programs have been used to provide data, which varies in usefulness

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